MY MS, MY RIGHTS MY CHOICES: PROJECT EVALUATION

Final Report

for MS Society

Welsh Institute of Health and Social Care (WIHSC)

University of South Wales

March 2020

CONTENTS

INTRODUCTION

This report presents the findings of the evaluation of the My MS, My Rights, My Choices programme provided by the MS Society. The My MS, My Rights My Choices service is an on-demand service provided by the MS Society. They offer advice and information on a range of topics, including:

- Employment rights and welfare benefits, including Personal Independence Payment (PIP) and Employment and Support Allowance (ESA) claims.
- Information on different ways to manage MS.
- Information on accessing treatments, health and social care services relevant to those with MS.

There are four project officers based in different regions of Wales who deal with the clients for the My MS service. They offer face to face and telephone appointments for clients who need the service.

The My MS service has four key outcomes. It is designed to have a positive impact on **beneficiaries** in respect of:

- Participation in their local community and improved well-being and independence (Outcome One),
- More choice and access to care and treatments (Outcome Two)
- Being better informed about their choices for social and leisure activities (Outcome Three)
- Greater financial security (Outcome Four).

WIHSC has been commissioned by the MS Society to evaluate the My MS, My Rights My Choices service. This report reflects the full findings of the evaluation, which began in 2018. An interim report was provided by WIHSC to the MS Society in March 2019.

METHODS

This evaluation used a variety of methods to collect data to evaluate the My MS, My Rights, My Choices programme. These are detailed below.

Beneficiary Survey

WIHSC designed a survey which has been disseminated by the My MS project officers to beneficiaries. This survey assessed a variety of information, from demographic information, to MS information, to experiences of the service and the impact it has had on individuals lives. 149 surveys were completed in total across the course of the evaluation.

Qualitative Interviews

Qualitative interviews were conducted with a variety of participants, including beneficiaries, area stakeholder board members, external stakeholders such as MS Nurses, and My MS staff. This enabled WIHSC to get a sense of the impact of the My MS service from a variety of perspectives. 28 beneficiary interviews were conducted, along with 5 individual interviews with Area Stakeholder board members. 3 interviews were conducted with Carers of individuals who used the My MS service, as well as 4 interviews being conducted with external stakeholders of the project. 2 individual interviews were conducted with My MS staff as well.

Focus Groups

Focus groups were conducted with the Area Stakeholder Board members. These stakeholder boards are made up of MS Society members with a stake in the project, and are divided across four regions – South West Wales, South East Wales, North West Wales, North East Wales. Focus groups were conducted in three out of the four regions to get a sense of the stakeholder board members perspectives on the project.

Digital Stories

Digital storytelling is the method of using computer-based tools to tell a story. They combine an audio recording of an individual's experience with still photographs. Four digital stories were completed by WIHSC team member Marina McDonald and provided to the MS Society as part the evaluation. In a similar fashion to the qualitative interviews, this method allows us to show the human side of those using this service, strengthened with a visual and digital component.

ALIGNMENT WITH WELSH GOVERNMENT POLICY

As part of the evaluation, we sought to analyse how the outcomes for the My MS, My Rights My Choices project sit in line with current Welsh Government Social Care policy and legislation.

National Outcomes Framework

The National Outcomes Framework in Wales 'puts in place a framework for meeting the challenges facing social services in the next decade and beyond, and sets out the priorities for action,' (NOF, Welsh Government)[1]. The policy sits alongside the Social Services & Well-Being Act and attempts to provide 'provide for a system that will be centred on the well-being of people who need care and support and carers who need support,' (NOF, Welsh Government).

National Outcomes Framework Well-Being Table

This is a copy of the well-being table from the NOF, detailing what well-being means from Section 2 of the Social Services & Well-Being Act, and the national well-being outcomes. These will then be analysed in respect of the My MS services stated outcomes and project deliverables.

What Well-Being Means	National Well-Being Outcomes
Securing rights and entitlements Also for Adults: Control over day-to-day life	I know and understand what care, support and opportunities are available and use these to help me achieve my well-being. I can access the right information, when I need it, in the way I want it and use this to manage and improve my well-being. I am treated with dignity and respect and treat others the same. My voice is heard and listened to.

[1] National Outcomes Framework, Welsh Government, available at https://gov.wales/sites/default/files/publications/2019-05/the-national-outcomes-framework-for-people-who-need-care-and-support-and-carers-who-need-support.pdf

	My individual circumstances are considered. I speak for myself and contribute to the decisions that affect my life, or have someone who can do it for me.
Physical and mental health and emotional well-being Also for children: Physical, intellectual, emotional, social and behavioural development	I am healthy and active and do things to keep myself healthy. I am happy and do the things that make me happy. I get the right care and support, as early as possible.
Protection from abuse and neglect	I am safe and protected from abuse and neglect. I am supported to protect the people that matter to me from abuse and neglect. I am informed about how to make my concerns known.
Education, training and recreation	I can learn and develop to my full potential. I do the things that matter to me.
Domestic, family and personal relationships	I belong. I contribute to and enjoy safe and healthy relationships
Contribution made to society	I engage and make a contribution to my community. I feel valued in society.
Social and economic well-being Also for adults: Participation in work	I contribute towards my social life and can be with the people that I choose. I do not live in poverty. I am supported to work. I get the help I need to grow up and be independent. I get care and support through the Welsh language if I want it.
Suitability of living accommodation	I live in a home that best supports me to achieve my well-being.

We can then compare these to the My MS service outcomes, as listed below:

My MS, My Rights My Choices Outcomes	
Outcome One	Positive impact on beneficiaries participation in their local community and improved well-being and independence
Outcome Two	More choice and access to care and treatments
Outcome Three	Being better informed about their choices for social and leisure activities
Outcome Four	Greater financial security

We can see that the first part of Outcome One, having a positive impact on beneficiaries participation in their local community, sits in line with the NOF outcome on 'Contribution made to society' which encompasses the well-being aim of 'I engage and make a contribution to my community'. We can see that the second part of Outcome One, 'improved well-being and independence' sits alongside the NOF outcome on 'Social and Economic Well-Being', where it states 'I get the help I need to grow up and be independent' and also alongside the 'Securing Rights and Entitlements' section, which states 'I can access the right information, when I need, in the way I want it and use this to manage and improve my well-being'. There is a large amount of data in the evaluation on the ways in which the My MS service positively impacted beneficiaries well-being and independence, and there is also data on the ways in which beneficiaries engaged more with their local community, via area stakeholder board meetings or local MS groups signposted by the My MS service.

Outcome Two, more choice and access to care and treatments for beneficiaries, sits alongside the section on 'Securing Rights and Entitlements' which states 'I know and understand what care, support and opportunities are available and use these to help me achieve my well-being'. It also sits alongside the section on 'Physical and Mental Health and Emotional Well-Being' which states 'I get the right care and support, as early as possible'. There is data in the evaluation on the ways in which the My MS service signposts beneficiaries to further care and support options for living with MS.

Outcome Three, beneficiaries being better informed about their choices for social and leisure activities, sits alongside the section on 'Social and Economic Well-Being' which states that 'I contribute towards my social life and can be with the people I choose'. It also aligns with the section on 'Domestic, Family and Personal Relationships' which states that 'I belong' and 'I contribute to and enjoy safe and healthy relationships'. It is clear from the data in the evaluation that people are assisted to become more social by the My MS service, and that they may feel a greater sense of belonging by attending My MS events or becoming an area stakeholder board member. The My MS service has been instrumental in bringing people with MS together, whether that is in the form of local MS groups, boccia groups or events such as the newly diagnosed days.

Outcome Four, greater financial security, aligns with the NOF section on 'Social & Economic Well-Being' which states 'I do not live in poverty' and 'I am supported to work'. The My MS service has certainly met this outcome, as will become clear in the section on PIP benefit, and in the survey responses on financial security. Many people have successfully used the My MS service for assistance to claim Personal Independence Benefit, and there is data in the chapter associated with PIP on the amount of money the My MS service has helped people win via PIP tribunals. The My MS service also assists those living with MS in dealing with issues with employers and working whilst living with MS. In this respect it meets Outcome Four and therefore is in good alignment with the NOF, and the Social Services & Well-Being Act.

SUMMARY OF ALIGNMENT WITH WELSH GOVERNMENT POLICY

We can see from this chapter that the My MS, My Rights My Choices project sits in good alignment with Welsh Government policy on social care, specifically with the National Outcomes Framework and the Social Services & Well-Being Act. All of its outcomes are aligned with sections of the NOF, and it will become clear from the data presented in the evaluation how the service has met its outcomes and how it works in conjunction with the key principles of the Social Services & Well-Being Act, including Voice & Control, Co-production, Prevention, Multi-Agency work (via signposting to other support, and through working with external stakeholders) and the Well-Being Principle. It is clear that the My MS service is well aligned with current Welsh Government social care policy, and the data presented in the evaluation will highlight this further.

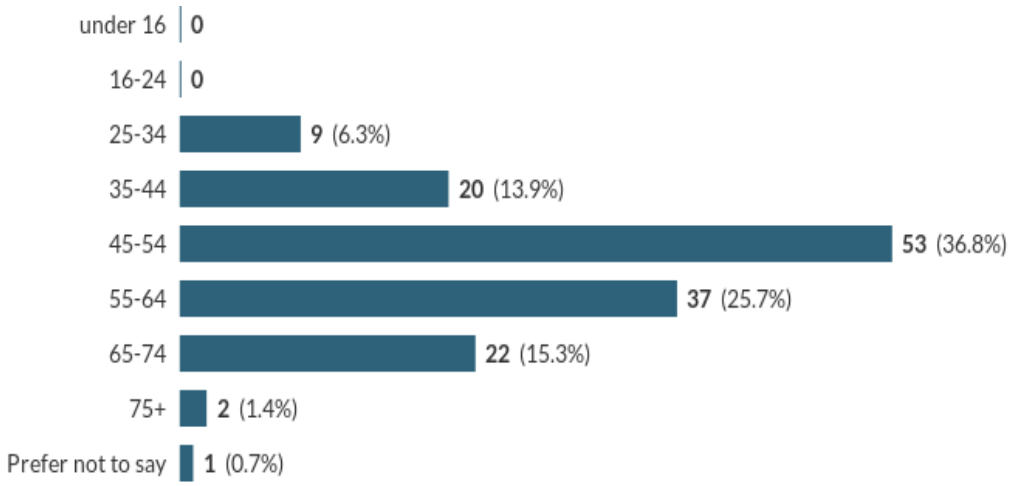
BENEFICIARY SURVEY RESULTS

This section of the report explores the results of the beneficiary survey. The survey was hosted online by WIHSC, and distributed by the MS Society to people who had experience of the My MS, My Rights, My Choices service. The survey could be completed by respondents either online or via hard copy. A total of 149 responses were received over the course of the evaluation.

DEMOGRAPHIC INFORMATION

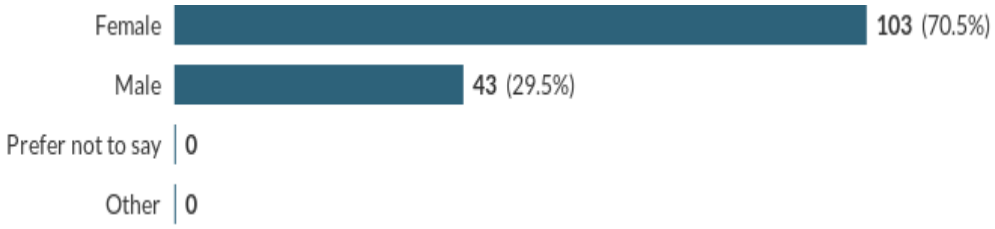
The first section of the survey explores demographic information for beneficiaries, including age and gender. This allows us to understand the demographic variety in the people who use the service and who responded to the survey.

Age of Respondents



We can see here that the largest percentage of people who use the service are aged 45-54 (36.8% of respondents). Second to this is the 55-64 age group, at 37 (25.7%) respondents. Aside from these two age groups, the answers are divided across the younger and elderly age groups with some variation.

Gender of Respondents

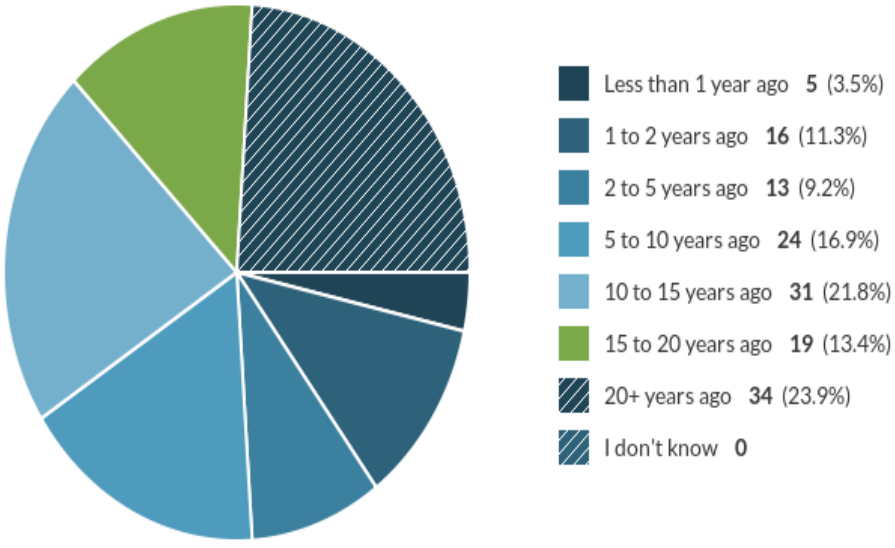


We can see from this graph that the majority of beneficiaries who responded to the survey were female, at 103 (70.5%) of respondents. 43 beneficiaries were male, which made up 29.5% of respondents.

MS INFORMATION

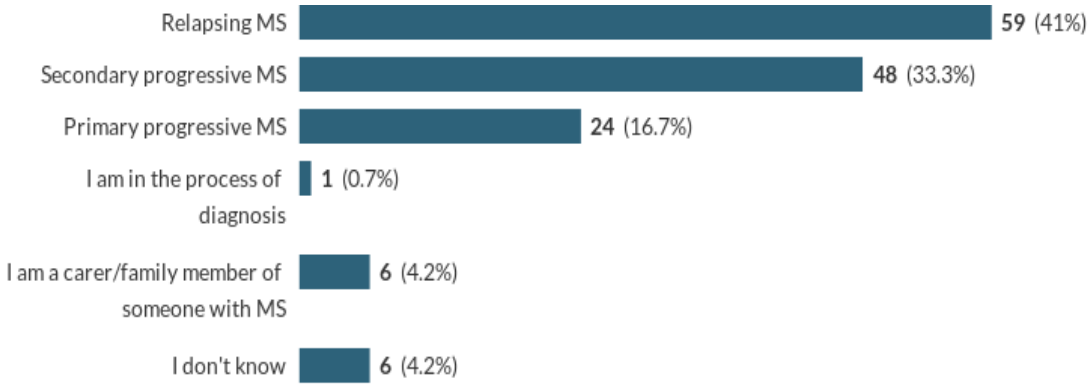
This section of the survey relates to information on beneficiaries MS conditions. It tracks the types of MS that beneficiaries have, as well as the length of time since their diagnosis. This enables us to get a sense of the variation in beneficiaries MS conditions.

When were you diagnosed with MS?



This question asked respondents how long ago they were diagnosed with MS. We can see that responses are spread fairly evenly across the time categories, with the most answered category being '20+ years ago', with 34 responses (23.9%). 21.8% of respondents answered 10-15 years ago, with 16.9% responding 5-10 years ago. This shows that people using the My MS service have been living with MS over various durations.

What type of MS do you have?

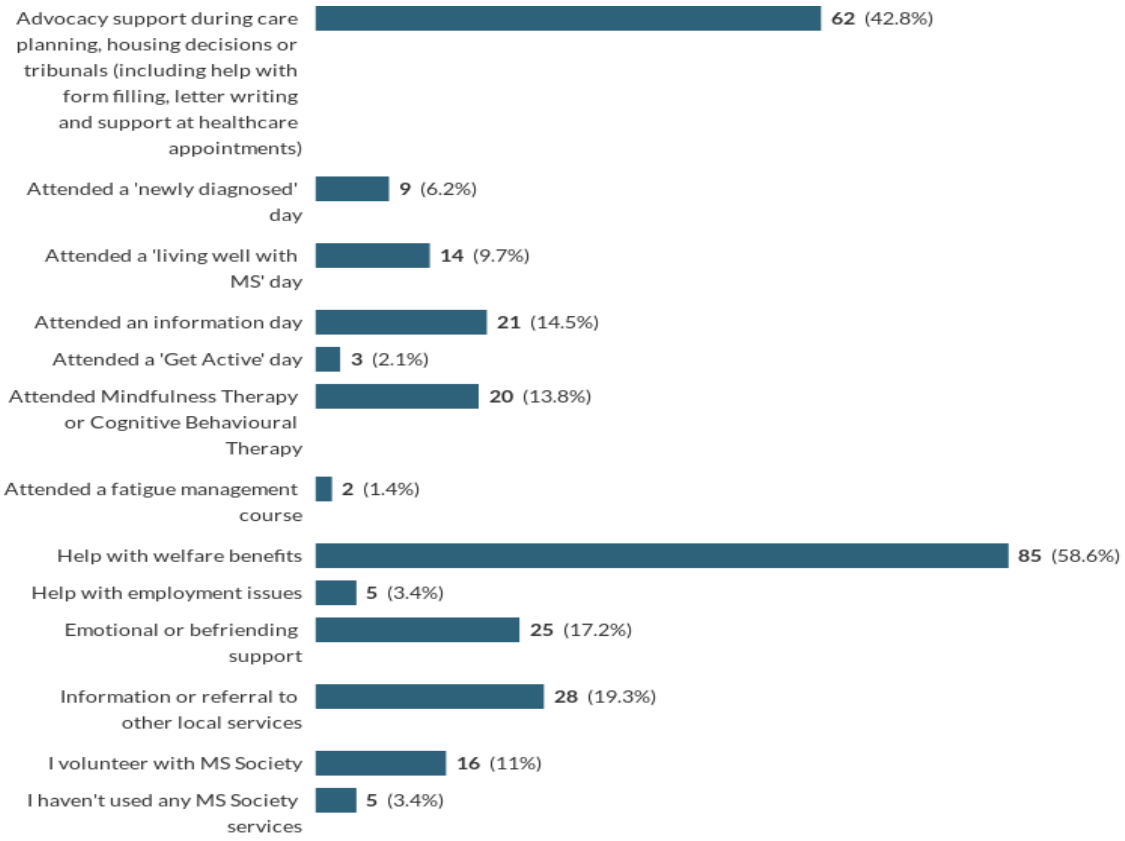


This section of the survey focuses on the different kinds of MS that beneficiaries are living with. We can see that 59 (41%) respondents answered that they have relapsing MS. The second most frequent kind of MS was secondary progressive MS, with 48 (33%) beneficiaries. Primary progressive MS was then the third response, with 24 (16.7%) of respondents.

EXPERIENCE OF THE MY MS, MY RIGHTS MY CHOICES PROGRAMME

This section of the survey is the most extensive, asking people to comment on a variety of experiences, primarily using the 5 point Likert scale, which ranges from Strongly Agree to Strongly Disagree. These responses are presented below.

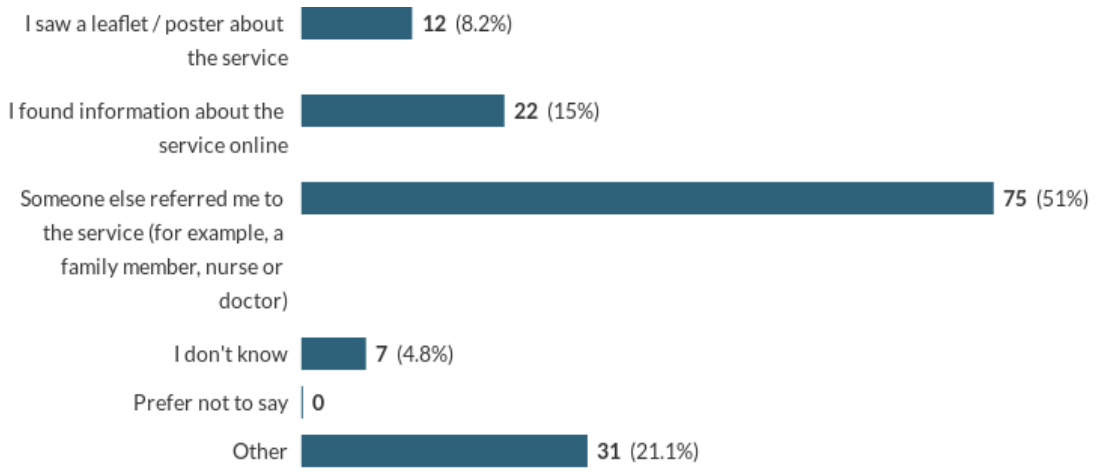
How has the My MS service helped you?



This section of the survey asks people to reflect on how the My MS service has specifically helped them. There are a variety of answers available, however the highest response was 'help with welfare benefits' at 85 respondents (58.6%). This fact is borne out in the qualitative interviews we conducted for the evaluation; one of the pre-eminent themes to arise from these interviews was the priority of assistance with the Personal Independence Payment (PIP). This ranged from help with filling in the PIP forms, to attending appeals and tribunals with beneficiaries. This theme is explored further in the qualitative interview section.

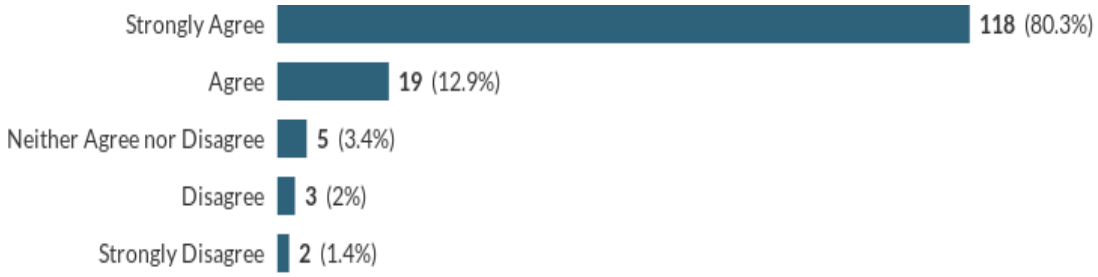
The second most responded to category in this section was support with care planning, housing decisions or tribunals, at 62 (42.8%). The rest of the responses centre around attending an event (e.g. a newly diagnosed day) or a course provided by the My MS programme, e.g. fatigue management. People also received assistance with employment issues and signposting to other useful services.

How did you hear about the 'My MS, My Rights My Choices' service?



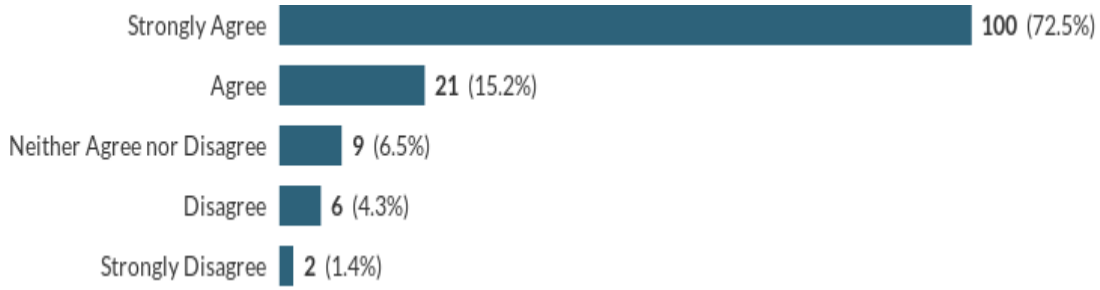
This questions asks respondents how they heard about the My MS service. The majority of people (51%) heard about the service via a referral, from a family member, nurse or doctor. This is borne out in interviews with external stakeholders from MS teams, who advised that they frequently referred people with MS to the My MS service.

I have had the right information and support when I needed it



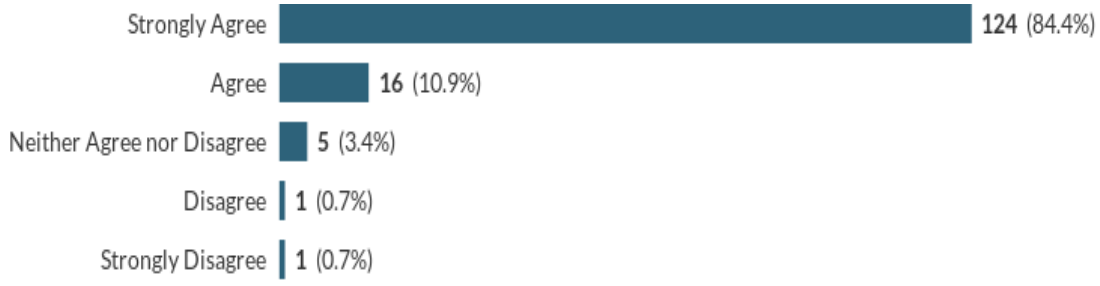
This section asks beneficiaries whether they feel they have the right information and support from the My MS service when they have needed it. The vast majority of people strongly agreed with this statement, with 118 (80.3%) respondents in this category. 19 people (12.9%) agreed with the statement, meaning that a total of 93.2% strongly agree or agree with this statement. This reflects extremely well on the My MS service in respect of giving beneficiaries the right information and support when they have needed it. This speaks to the outcomes of the My MS service around beneficiaries being better informed about support and care options.

I have been actively involved in decisions about how my information and support was provided



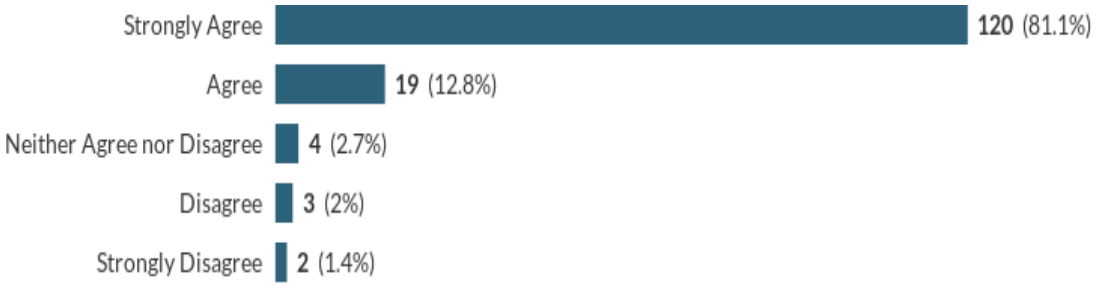
This question asked beneficiaries whether they felt they had been actively involved in decisions about how their information and support was provided. Again, the results here are extremely positive for the My MS service, with 72.5% of respondents strongly agreeing with the statement, and 15.2% of respondents agreeing with the statement. This means a total of 87.7% of respondents strongly agreed or agreed with the statement that they have been involved in decisions about how information and support is provided to them. This falls in line with Welsh social care policy and legislation, particularly the Social Services & Well-Being Act which prioritises co-production and voice and control as key principles in social care.

I was treated with dignity and respect



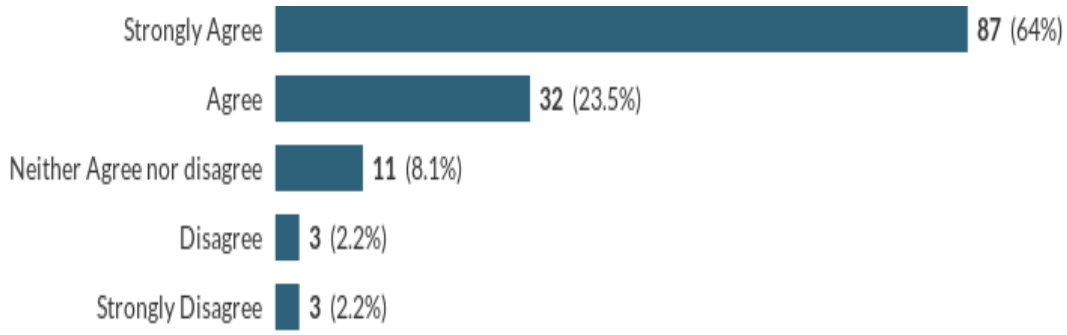
This question asks people if they feel they were treated with dignity and respect when using the My MS service. Again, the results reflect very positively on the My MS service, with 84.4% of respondents strongly agreeing with the statement, and 10.9% agreeing with the statement. This means a total of 95.3% of respondents feel they were treated with dignity and respect by the My MS service. This has positive implications for the ways in which the My MS service is meeting its outcomes and also the principles of the Act, particularly around well-being and voice and control.

I know who to contact if I need help



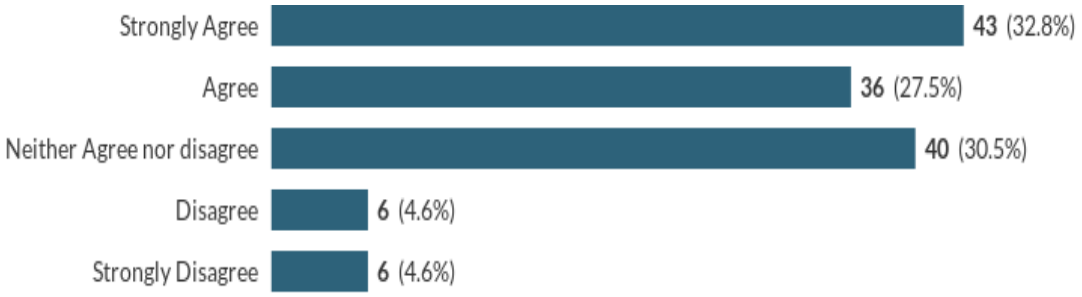
Respondents were asked if they know who to contact if they need help. 81.1% of respondents strongly agreed with the statement, with 12.8% agreeing with the statement. This shows that beneficiaries feel well-informed by the My MS service about who they should contact if they need help. This means that the service is accessible and provides clear information to its beneficiaries.

I feel better informed about my MS and the support I can get



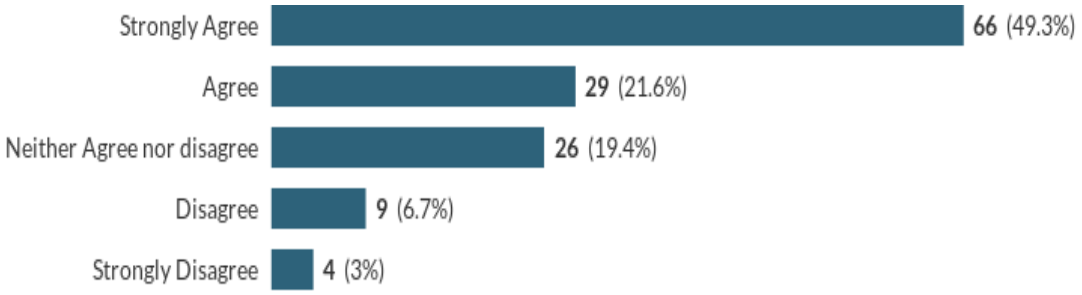
Here again we can see a broadly positive response to this question. 64% of respondents strongly agree that they feel better informed about their MS and the support they can get, and 23.5% agree with the statement. This gives a total of 87.5% of respondents who agree or strongly agree with the statement. This shows that the My MS service is performing well in respect of its stated outcomes, particularly outcome two, which aims to have a positive impact on beneficiaries in respect of 'more choice and access to care and treatments (Outcome Two)'.

I feel more able to participate in social and leisure activities



This question speaks to outcome three of the My MS service, which is that beneficiaries will be 'better informed about their choices for social and leisure activities (Outcome Three)'. We can see that results are slightly more varied for this question than the previous questions; 32.8% strongly agree, 27.5% agree, however 30.5% of respondents neither agree nor disagree. This could perhaps be because of issues relating to their MS which are hindering their ability to participate in social and leisure activities, despite the best efforts of the My MS service. It could be that they were not looking for support in this area from the service. Nevertheless, 60.3% of respondents strongly agree or agree with the statement, and this is a positive result for the My MS service in respect of outcome three.

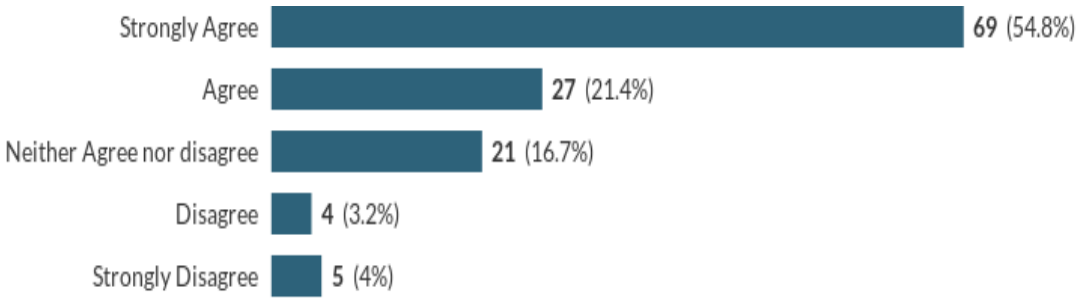
I feel more financially secure



This question allows us to see where the My MS service sits in regard to its fourth outcome, which aims for 'greater financial security' for its beneficiaries. We can see here that 49.3% of respondents strongly agree with the statement that they feel more financially secure, with 21.6% of respondents agreeing with the statement. That gives a total of 70.9% of respondents who strongly agree or agree that they feel more financially secure. This bodes well for the My MS service meeting its fourth outcome regarding financial security for beneficiaries. It may be that beneficiaries received help from the My MS service in obtaining

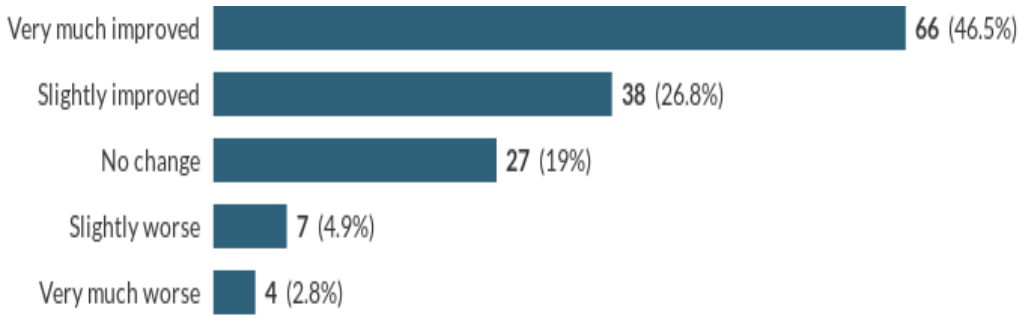
Personal Independence Benefit (as is borne out in the interviews), attending a PIP tribunal, or applying for an MS Society grant.

The service has helped me get support from another agency/person



For this question, 54.8% of respondents strongly agreed with the statement that the My MS service has helped them to get support from another agency/person, with 21.4% agreeing with the statement. This gives a total of 76.2% who agree or strongly agree that the My MS service has helped them get support another agency/person. This question doesn't fall as neatly in line with a stated outcome as some of the others, although it could be linked to outcome two 'more choice and access to care and treatments'. Broadly speaking though it shows that My MS beneficiaries feel that they have been signposted to further support services or people after using the My MS service.

How would you describe any changes in your well-being (how you are feeling and how well you can cope with day-to-day life) since being in contact with My MS project officer?



We asked beneficiaries to describe any changes in their well-being since coming into contact with their My MS project officer. 46.5% of respondents said that their well-being had been very much improved since coming into contact with My MS staff. 26.8% said their well-being had been slightly improved. This makes a total of 73.3% of respondents who felt their well-being had improved since coming into contact with their My MS project officer. This links to

outcome one of the My MS service, which states beneficiaries should see a positive impact in respect of their 'well-being and independence'. The answers to this question show that the My MS service is meeting its targets in respect of outcome one.

Open text reflections

Respondents were then invited to reflect on their reasons for their answers to the above question, and their experiences with My MS staff. A selection of these reflections are presented below. Please note that individual project officers names have been removed for anonymity purposes.

> *'Before I was put in contact with [project officer] I was in a very bad place mentally, physically, emotionally and financially. [Project officer] has helped me through a DWP tribunal to get my ESA back, helped me get my blue badge, helped me get P.I.P, and is also helping me to apply for a mobility scooter.*
>
> *Before speaking with [project officer] I had no idea how to get through these things, with her help I am now more able to get on with life knowing that someone is there to help if needed, without her help I know I would still be in the same bad situation as I used to be.*
>
> *[Project officer] has been a massive support resource for me and I feel so much more confident knowing that she is there to help me and others when needed.'*
>
> *'[Project officer] is very friendly and approachable, we have become good friends. She explains everything fully. She helped me to change from DLA to PIP even though it was very stressful, we got through the process together - I wouldn't have done it without her.'*
>
> *'[Project officer] was very knowledgeable about what and where I could claim and helped completing forms to claim benefits.'*

Here we can see the variety of ways in which My MS staff had a positive impact on beneficiaries lives. From technical and practical knowledge, to emotional and pastoral support, these quotes show the ways in which the My MS project officers occupy an essential role in many beneficiaries lives.

Would you recommend the 'My MS - My Rights, My Choices' service to others

We asked respondents whether they felt they would recommend the My MS service to others. The results here are an overwhelmingly positive reflection on the My MS service from beneficiaries, with 87.9% of respondents stating that yes, they would recommend the My MS service to other. This overwhelming response shows the positive experience that beneficiaries have been having with the My MS service during the course of the project.

The 'My MS - My Rights, My Choices' service is currently funded until 2020. Do you think it should continue beyond this date?

We then asked respondents whether they felt the service should continue beyond its funding date in 2020. An overwhelming majority of respondents felt the service should continue, with 93.2% answering 'yes'. Only 1 respondent felt the service shouldn't continue beyond its funding date. This is an overwhelmingly positive response from beneficiaries here, with almost all respondents feeling that the service was so valuable that it should continue beyond its funding end date.

Please give a reason for your answer

We then asked respondents to give an open-text reason for their previous answer regarding the continuation of the My MS service beyond its funding end date. Some of the responses are presented below:

> *'It is vitally important that people have someone who can help when people need it'*
>
> *'The service has helped me greatly and I think the service should remain so that others can get the same sort of help that I have received.'*

'Without a doubt this service is very much needed. Without it we felt rather isolated and vulnerable, unsure of where to turn and what to do at times.'

'As a newly diagnosed person I had no idea about benefits and rights at work. This service has reduced my stress and anxiety.'

We can see from these quotes some of the reasons why beneficiaries of the My MS service feel that the service should continue beyond its funding end date. Many respondents identify the need for people with MS to have someone to turn to, beyond clinical consultants and MS nurses, to help deal with practical, financial, and social aspects of living with MS. One of the quotes points to the potential for feelings of isolation and vulnerability to be exaggerated and exacerbated should the service not be available. We can also see the importance of the service for newly diagnosed beneficiaries, as the last quote indicates the My MS service has helped with information around benefits and employee rights, which has had a positive knock-on effect on that individuals' stress and anxiety levels.

SUMMARY OF SURVEY RESULTS

We can see from the results presented above that beneficiaries are largely having a positive, rewarding experience when using the My MS service. We can see that the My MS service is meeting its stated outcomes, particularly around improved well-being and independence, financial independence, and better informing beneficiaries about care and support options. We can see that many beneficiaries would recommend the service to others, and that an overwhelming majority would like to see the service continue beyond its funding end date. We can also see the impact that the service has had on beneficiaries from the open text responses, where beneficiaries have discussed the positive impact that the service has had on their well-being, benefits applications, sense of isolation and loneliness, and understandings of employment rights. Overall, the survey results show that the My MS service plays an important role in people's lives, has a positive impact on their lives, and is meeting its stated outcomes in most areas.

PERSONAL INDEPENDENCE PAYMENT

We found, through the process of conducting qualitative interviews and attending area stakeholder board meetings, that the priority area of support for most beneficiaries was assistance with the Personal Independence Payment. We have therefore dedicated a chapter to the assistance people have received with this benefit from the My MS service. This section will encompass interviews from beneficiaries, reflections from My MS staff on the tribunal process, and financial data received from My MS staff on the amounts of PIP benefit awarded to beneficiaries via tribunals during the course of the My MS project.

The PIP benefit replaced the Disability Living Allowance, and those individuals living with MS who were already receiving DLA still had to apply anew for PIP and be assessed by benefits assessors as to whether they qualified for the new benefits. The DWP has been asking DLA claimants to apply for PIP over the course of the My MS project, and this need to apply for the new benefit has seen this assistance with the PIP claiming process become one of the priorities for the My MS service. The quotes presented below highlight some of the ways in which the My MS service has assisted people with PIP.

> *'Yeah they helped me, uh he also helped me with my PIP, um to help me to fill out the forms and when I couldn't speak my PA spoke on my behalf, and he filled out the forms, um and then when he knew all about me and everything, filled it out sent them off and then when they came back then I spoke with him again, but my PA was in the interview that I had at home, and that was all done through [project officer], he arranged all of that you see, and I had uh the PIP interview at home, and after one or two weeks the forms came back and I had been awarded the um I can't say the word, oh the enhanced award, and that's what [project officer] was helping me to fill out the forms for, of course I had been worried for 3 or 4 years because I had not had these forms land on my door, and of course when they do come to your home they still make you very nervous, and anyway I was enhanced, I had the enhanced award, and yippee-yay- yay you know, and I told [project officer] about it, and that was all good' (Interview with Beneficiary)*

The above quote encapsulates many of the issues My MS beneficiaries face around applying for PIP, as well as the successes achieved by the My MS service in allaying those issues. The beneficiary here highlights how she had help from My MS staff in filling out the PIP forms, which was a sentiment echoed in many other interviews we conducted: the PIP forms themselves are intimidating and lengthy, especially for those living with MS who may have cognitive or visual impairments.

We then see the way in which the My MS project officer assisted in helping with arranging the PIP assessment, and that the beneficiary was in fact awarded the enhanced PIP benefit award, which they were very happy about.

These next set of quotes show the journey the beneficiary went on with their PIP claim and the support they received from the My MS service.

> *'Oh yeah. Definitely. Yes, I mean you know [project officer], he came to the house within a couple of days, went through the whole of the form with me, helped me with the understanding of the form, and also wrote the form for me, because my dexterity is not so good.' (Interview with Beneficiary).*

Here we can see how the project officer assisted the beneficiary by coming to their home, within a couple of days of being contacted, and then helping them fill out the PIP form, particularly as this beneficiary has difficulties with their dexterity.

> *'No, the claim has gone through. And um I ended up getting the higher payment than I had before, I ended up getting the enhanced payment for living allowance, and an enhanced payment for the mobility. So yes, he was very very good.'*

The following quote from the same interviewee later shows that not only were they successful in receiving their PIP benefit, but that they too also received the enhanced award for both living allowance and mobility. This again shows the successes of the My MS service in assisting people with their PIP benefits.

> *'Interviewer: How did you come to hear about the My MS, My Rights My Choices service?*

Beneficiary: Well what happened was, I had my letter to say that obviously um my DLA was coming to an end and I had to apply for PIP, so um I rung my MS Nurse, and she um gave me gave me the number, for [project officer].

Interviewer: And then what were you looking for support with when you contacted My MS, was it purely the PIP forms and that kind of things?

Beneficiary: Yes, yeah um yes basically, um well I was just in a panic and um [project officer] calmed me down, and explained everything and told me not to panic, and then um she went through things on the phone and then she said to me, look I can meet you, so that was just well, you know, that just put my mind at ease and everything, so she was great.'

This extract shows the pastoral and holistic element to the support that the My MS project officers supply around the PIP benefit. Having to re-apply for benefits was obviously very stressful for people living with MS, and this extract shows the way in which the project officer calmed the beneficiary down, explained everything to them and then arranged to meet them to go through the PIP claim. It became clear, through the course of the evaluation, that My MS staff offer two distinct but overlapping types of support: practical and technical help, e.g. with the PIP forms and other information, and holistic and emotional support, by helping people deal with their stress and anxieties around things like PIP claims and other issues.

REFLECTING ON THE PIP TRIBUNALS

As the theme of support with PIP claims became more evident throughout the evaluation, we thought it important to get the voice of My MS staff regarding this issue, with a particular focus on the ways in which beneficiaries have been supported through PIP tribunals. We interviewed two of the My MS staff who have both been in post throughout the project, asking them to reflect on the tribunal process, and how it affects beneficiaries support needs.

Why do people have to go to tribunal?

'People apply for PIP and then a lot of people who I supported to go to tribunal are actually people who have been on DLA….Disability Living Allowance….so they've been

on that at quite a high rate and then they get their PIP and then they are not awarded enhanced…there's only two levels of PIP…so there's the standard and the enhanced whereas on DLA there was three levels of award….so a lot of people lose out financially in that transition over to PIP…..the first stage of appeal for PIP is something called the mandatory reconsideration….where we've just ask….you appeal to the DWP….so we ask the DWP just to relook at it….we can submit more evidence at that stage and often do….but we know that something that 84% of those just get turned down….even though you present a very fair case…..there's only 16% of those will actually….around about that….only about 16% will get through at MR stage….which means your next stage of appeal is to go to court…go to tribunal…so that's how we end up then going to tribunal with quite a number of people….I think we've done about 20…..probably up about 31….about 10 a year we are supporting to go to tribunal and that's just the people we know about…..' (Interview with Project Officer)

Here, the My MS project officer reflects on the reasons that cause beneficiaries to have to go to a PIP tribunal. She notes that some people who transfer over from DLA do not get the same level of award as they were previously receiving. This can have a drastic effect on people's lives, including the loss of mobility and transport. The project officer notes that claimants can appeal via mandatory reconsideration, but that 84% of these appeals get turned down. Once this has happened, the only option left available to the claimant is to go to a tribunal. The project officer note that the project is supporting around 10 people a year to go to tribunal.

Preparing for tribunal

We asked the project officers how they go about preparing for the tribunal with beneficiaries that they support.

'So um I'll verbally go through with them – so usually there's sort of like two face-to-faces, once we've done the paperwork to go to tribunal, then I'll um meet with them and prepare what we call a submission document, so it's usually a two sided piece of paper or up to two sides, that's got all of the very much the reasons why we feel, and the claimant feels they should be awarded the benefit, so um collecting sort of evidence and any sort of case law that backs it up, as well as verbal testimony, um and

very much then suggesting to the tribunal that you know two points should've been awarded for eating and drinking, and four points should've been awarded for washing and bathing, and so presenting that as a um I guess a summary sheet to the tribunal panel members, because the tribunal panel members themselves will have a hundred-odd pages to go through, we find – I found in a previous job we were advised to do this, and then since then we've done training and they concurred very much to produce this sort of summary sheet, uh that sort of focuses the panel members minds, as well as the claimant's mind as to what he or she will be talking about, so yeah so usually I'll meet with them, we'll prepare, I'll make notes, go away and then I'll go back again with the finalised sheet, ensure that they're happy with it, also talk through the actual practicalities of the day with them, what to expect how many panel members, um the length of time, the sort of common questions that get asked all the time, um so they're sort of not coached but they're well prepared, and then so once that's all agreed then once we've got the actual dates of the tribunal then yeah then we'll have a few phone calls just to confirm that I'm available, um you know reassure any last minute questions and then I'll send in usually seven days before the tribunal send in the submission document.' (Interview with Project Officer).

The above extract shows the detailed levels of preparation that goes into getting beneficiaries ready for their PIP tribunal. This involves preparing the submission document for the tribunal panel, with the beneficiary, then submitting this and also talking through the events of the tribunal itself, what the day itself will look like. The project officer notes how going back and forth with the beneficiary during the build up to the tribunal helps to assuage their fears and anxieties about the tribunal, and enables them to be properly prepared for the questions they are likely to face on the day from the tribunal panel.

Emotional Support

'Absolutely…..yeah….it's exactly that….the technical stuff of get the paperwork submitted to court…start drafting the submission for court…and then the hand holding all the way along….I've had an email off someone this morning where we are down for his tribunal and he's well 'I really need a holiday' so we are going to just go on holiday….I'm like yeah just go forget about it…..if you get your tribunal date when you're away we'll sort it out when you come back….so there's a lot of anxiety…a lot of

emotions go around….a lot of people with MS deteriorate you know cause stress and MS don't go hand in hand so people can get quite poorly and I get feedback particularly wives and husbands saying they are not going out….their mood has dropped….I'm really worried about them….all of that goes on during that period of getting to tribunal…so it is a lot of hand holding….a lot of emotional support…pastoral support as you described it…for both you know the person who is going to court and if they have a wife, husband, partner….a lot of that happens yeah….' (Interview with Project Officer)

The above quote highlights further the need for emotional support for beneficiaries during the tribunal process. As the project officer indicates, there can be a long period of waiting for the court date to be determined, sometimes over 6 months, and this period involves a lot of emotional support for beneficiaries as they wait anxiously for their court date. We can also see that once the date is confirmed, then the emotional support the project officers are expected to give potentially increases, as beneficiaries become more and more anxious and deal with higher stress levels approaching the tribunal date. The project officer also notes how the emotional support isn't limited only to the beneficiary themselves, but also to the beneficiaries significant other or life partner. These people have a lot at stake during these periods and the project officer notes that they may frequently have to support those individuals as well as the beneficiaries themselves.

The Tribunal Day

These quotations describe the success of the My MS service in tribunals and the way in which the tribunal process plays out on the day.

'Yeah….we've had 100% success….so we've had one person whose benefit was maintained…they didn't get an increase….but they were still awarded it and then everybody else had an increase in their award….I think it was just before Christmas and so what I always say to people is once you get into court you are in front of a judge….he's not employed by DWP….they are impartial….there's someone a GP or Doctor there…sometimes we don't know whether they are a GP but they tend to be GP's who'll know the condition and then there's an independent person and that's always a person with experience of disability…..I always think it's a very fair hearing

once you get into court….I always say to people once you get in front of them they are not swayed by the DWP….the DWP can send a representative and sometimes they do and they can ask questions but they have no bearing on the decision of the court….it is a decision made by court and the decision is made….[project officer] probably explained to you….on whether or not the decision was right on the day that the decision was made….so you know sometimes we can be looking back 9 months and saying 9 months ago that decision wasn't right and sometimes the judge will say so how is life for you now and people say well actually it's been really awful cos I've had no money…I lost my car….my mobility is gone…my mental health is deteriorating….that sort of stuff….but they tend not to want to know really what's happened in that period….that's where we pick up the pieces…..the decision is was the decision right on the day that it was made….and then the court decides whether it was or not based on the evidence that we give them……its quite a….very stressful, very emotional…..but I feel it quite fair for people who have a strong case definitely I would encourage them to go to court….' (Interview with Project Officer)

We can see from the above extract that the My MS service has been extremely successful in dealing with PIP tribunals, with a 100% success rate so far. The project officer discusses the ways in which the tribunals are different from the appeals process, as they are processed through the courts and not through the DWP. They explain the ways in which the tribunal panel differs from the DWP appeals process, and how beneficiaries are more likely to get a 'fair' hearing at the tribunal. They note that it can be 'very stressful, very emotional' for beneficiaries, and that part of their role is to offer emotional support through this process.

Benefits for beneficiaries of My MS support during tribunal

We asked staff to reflect on what they thought the benefits for beneficiaries were in having the My MS service support them through the tribunal process.

'Interviewer: Ok, I just wondered whether um or what your perspective is on the benefits for individuals to have you present, or whoever it is, when they're going to tribunal, what you think they get out of it?

Project Officer: Yeah, I get the same feedback every time, people have said to me 'oh I couldn't have done that without you' even the times when I've literally said nothing

the whole tribunal, because there's been a few times, a couple of times when we've walked in and the judge has said 'ok we've already made a decision in your favour' um and then there's been times where it's been really clear that in all the testimony that has been given they're scribbling away, they're sort of nodding in agreement especially with those little extra points to get the enhanced rate, sometimes I don't need to say anything cause I think you've made a decision, and then we come out and then usually there's like a ten minute waiting period and we get called back in for the decision, yeah and the individual says 'oh I couldn't have done that without you' and I suppose they're talking almost holistically and just having someone with them who kind of understands the system, the process you know more than just having a family member or whoever with them, so yeah there's – and I'm sure in some of your interviews you've spoken to some of the people we've assisted at tribunal, I hope they've probably said the same things, I think it's probably invaluable, the amount of times when I've when I'm preparing someone for a tribunal and we've sort of received the documents and we're a month-two months away from getting a date, and I always say you know I should be able to come with you, and you know I'll try and do everything I can to clear my calendar, and but if I can't it'll be ok because we'll have prepared this document and that's alright, and every time the person says 'oh no, I really hope you're able to come' and although I say you know 95% of the time of the talking its going to be down to you, they're going to give me very little actual time to speak, it's oh I really want you there, and it is that thing about having someone with experience and knowledge, just to do the hand-holding, because actually it takes so much time, um you know practically the tribunal tomorrow, Monday sorry, I'll allow an hour for everything, decision, and then it will be an hour to get there an hour to get back, fifteen minutes beforehand, so there's that time, then there's probably took me the best part of a day to write the submission for the individual, you know, a few more hours to actually do the document, to prepare for the tribunal. So it's really labour intensive, and the actual being there itself you know it takes a long time, and I get about a five minute window to actually speak, not even that! But from the individual's perspective it's like invaluable having me there, you know that sounds slightly big-headed.' (Interview with Project Officer)

The above extract highlights in detail the benefits for My MS beneficiaries of having My MS staff support them through the PIP tribunal process. The project officer notes that their role on the day of the tribunal is largely one of emotional and moral support for the beneficiary. The importance of having somebody there on the day who 'understands the system' seems invaluable for the beneficiaries. The project officer details the preparation before going to tribunal and what happens on the day, and how labour intensive the process is. They note how they feel that the support they give beneficiaries is invaluable to beneficiaries, which is supported by feedback they receive from beneficiaries they have supported through the tribunal process.

MY MS DATA ANALYSIS: PIP BENEFITS AND TRIBUNAL DATA

As part of the evaluation we received data from the My MS service on the PIP benefits that have been awarded at PIP tribunals for beneficiaries. We present some of this data below to show the financial successes that the My MS service has had for beneficiaries through PIP tribunals. This relates specifically to My MS outcome number 4, which is to achieve positive impacts for beneficiaries in respect of 'greater financial security'.

Table 1: South East Wales – Tribunal Representation

Person	Previously		Tribunal Decision		Financial Increase per year	
	DL	Mob	DL	Mob		
Beneficiary 1	Standard	Standard	Enhanced	Enhanced	**£3,481.40**	
Beneficiary 2	Standard	Enhanced	Enhanced	Enhanced	**£1,505.40**	
Beneficiary 3	None	Enhanced	Enhanced	Enhanced	**£4,557.80**	
Beneficiary 4	Standard	Enhanced	Enhanced	Enhanced	**£1,505.40**	
Beneficiary 5	Standard	Standard	Standard	Standard	**£0.00**	
Beneficiary 6	None	None	Enhanced	Enhanced	**£7,740.20**	
Beneficiary 7	Standard	Standard	Enhanced	Enhanced	**£3,481.40**	
Beneficiary 8	None	None	Standard	None	**£3,052.40**	
Beneficiary 9	Standard	Enhanced	Enhanced	Enhanced	**£1,505.40**	
Beneficiary 10	None	None	Enhanced	Enhanced	**£7,740.20**	
Beneficiary 11	Standard	Standard	Enhanced	Enhanced	**£3,481.40**	
					Total	**£38,051.00**

We can see here the successes for the Project Officer in South East Wales in assisting beneficiaries in winning PIP awards at tribunal. The table shows their previous allowance from their PIP claims, and then their rate after the tribunal. Allowance is split between DL (Disability Living) and Mob (Mobility). Almost all beneficiaries in this table received a higher

rate than what they were previously awarded. We can see that for almost all beneficiaries there was a financial increase in their benefit award. In total, across these 11 beneficiaries, there was an increase of £38,051 in PIP awards for this region and this project officer.

Table 2: South West Wales – Tribunal Representation

Person	Previously		Tribunal Decision		Financial Increase per year	
	DL	Mob	DL	Mob		
Beneficiary 12	Standard	Standard	Standard	Enhanced	**1976.00**	
Beneficiary 13	0	0	Standard	Standard	**6235.00**	
Beneficiary 14	0	0	Enhanced	Enhanced	**7741.00**	
Beneficiary 15	Standard	0	Standard	Enhanced	**3182.00**	
Beneficiary 16	Standard	Standard	Enhanced	Standard	**1505.00**	
Beneficiary 17	0	0	Standard	Enhanced	**6234.00**	
Beneficiary 18	0	Standard	Standard	Enhanced	**5028.00**	
Beneficiary 19	Standard	Standard	Enhanced	Enhanced	**3481.00**	
Beneficiary 20	0	0	Standard	Standard	**4258.00**	
Beneficiary 21	0	0	Standard	Enhanced	**6234.00**	
					Total	**45874.00**

Here we can see the successes of the project officer for South West Wales. Similarly, the majority of people were awarded a higher rate than what they previously received, with some beneficiaries going from 0 award to an enhanced rate. In total, the project officer for South West Wales brought in an increase of £45,874 for 10 beneficiaries, which is an average increase of £4587.4 across the ten beneficiaries who went to tribunal.

We can see from this data on tribunals that the My MS service is meeting its fourth outcome on providing greater financial security for its beneficiaries. We can also see from the staff reflections on the tribunals process the ways in which the My MS service provides valuable practical and emotional support during what can be a very stressful time. This helps people with their well-being as well as their financial security.

PIP BENEFIT: SUMMARY

We can see from this chapter of the report how important supporting beneficiaries with the PIP benefit was to the My MS, My Rights My Choices service. We can see from the interviews the ways in which My MS staff assisted people with the PIP benefits, from talking

them through the application forms, or even filling in the forms for them, to attending assessments and tribunals. We can see from the reflections of staff members on helping beneficiaries through the tribunal process the ways in which beneficiaries were helped through this process, from preparing for the tribunal date, filling in the summary sheets, helping to assuage any fears and worries of beneficiaries and their spouses or family members, to attending on the date of the tribunal and being there for emotional and moral support. Finally we saw the financial data on the amounts of money that the project officers in South Wales have helped generate for beneficiaries going to tribunals. The evidence in this chapter shows the the My MS service is meeting its outcomes, particularly around well-being, independence and financial security. It also shows us how much of a priority supporting those living with MS through claiming for PIP benefit was to the My MS project.

INTERVIEWS

In total, 42 qualitative interviews were conducted as part of the evaluation of the My MS service. 28 beneficiary interviews were conducted, along with 5 individual interviews with Area Stakeholder board members. 3 interviews were conducted with Carers of individuals who used the My MS service, as well as 4 interviews being conducted with external stakeholders of the project. 2 individual interviews were conducted with My MS staff as well.

This section will use the qualitative data collected during the evaluation to understand further the impact that the My MS service has had on beneficiaries, carers, stakeholders and staff. This will help us to illustrate the ways in which the My MS service is meeting its stated outcomes, and will also explore the variety of support needs that beneficiaries who use the service have. This section of the report is divided into sub-sections which explore each interviewed group, and within those sub-sections are further thematic divisions, based on themes observed within the data. Firstly, we analyse the beneficiary data collected in the interviews (aside from discussion of the PIP benefit, which was included in the previous section).

BENEFICIARY & CARER INTERVIEWS

This section focuses on the findings from the beneficiary interviews. Interviews were conducted over the telephone, with beneficiaries who had left their contact details when they completed the beneficiary survey. This section follows some of the themes and questions that were apparent during the beneficiary interviews.

How did you come to be involved in the My MS service?

We asked beneficiaries how they heard about or came to be involved in the My MS service. Below are some of the responses.

> *'My wife heard about it through Morriston hospital' (Interview with Carer)*

> *'Well what happened was, I had my letter to say that obviously um my DLA was coming to an end and I had to apply for PIP, so um I rung my MS Nurse, and she um gave me gave me the number, for [project officer].' (Interview with Beneficiary)*

'Um, I was on DLA and they sent me a letter to say that it was changing to PIP, and I got a bit confused with it all, and I went to see my MS nurse, and she recommended that I get in touch.' (Interview with Beneficiary)

'I heard from them through my local MS nurse. She told me about it.' (Interview with Beneficiary)

Here we can see that many beneficiaries were referred onto the My MS service via external stakeholders, such as MS Nurses or Hospitals. This is borne out by the interviews we conducted with external stakeholders, who confirmed that they frequently referred patients to the My MS service for assistance with issues outside of their medical remit (this is explored in a later section on external stakeholder interviews).

Support Needs

We asked beneficiaries what their support needs were when they contacted the My MS service – what did they need assistance with? Some of the answers are presented below.

'It was through um my wife's benefit which was going to PIP and we needed help, we weren't sure – we were hearing a lot of bad reports of people getting tripped up with the application, the new application where they were moving it from DV – what was the old benefit to the new benefit? A lot of people getting tripped up with it, so we decided to speak to people who were more on a regular basis you know in contact with this application. He very kindly come out at short notice, helped us with the application, made sure we fully understood everything on the application, no it was good' (Interview with Carer)

' Well, having MS, I wanted to see what was available, you know I've had MS for close to twenty years, and you know, it has its ups and its downs, and when things are not going so well then uh there's a need to sort of look out for support. I used to have the disability living allowance, that's now become the PIP, and I wanted some help because its very difficult to sort of come across with things that you're feeling and how things are in your general sort of day-to-day life and you know I just needed some support to help myself sort of go through this PIP process and find out what I needed to do, you know because as far as MS is concerned, a lot of the time it comes across as a sort of invisible illness, so

people don't see what you're going through, so that was my main reason for using the My MS.' (Interview with Beneficiary)

'She's been on a few different courses, which she's really enjoyed, yeah and obviously the help they gave us last year you know? They applied for charities to give money towards our ground rent that we have to pay for the year,' (Interview with Carer)

Here we can see some of the support needs that beneficiaries have had when approaching the My MS service. The first quotation, from a carer of someone with MS, asserts that they needed help moving from Disability Living Allowance to PIP, and how the My MS project officer came out to their home address to assist them with their PIP forms.

The second quotation also highlights the need for assistance with the PIP benefit, and how the person struggled to articulate their experience of living with MS on the PIP application forms, describing how MS can be what they term 'an invisible illness.'

The third quotation highlights some of the other areas of support that the My MS service offers, from courses on mindfulness and fatigue management to grant applications. In this instance the carer noted they were looking for assistance with their ground rent, which they confirmed they did receive after accessing support from the My MS service.

Overall Experience of My MS Service

We asked people to reflect on their overall experience of the My MS service. A selection of these answers are presented below.

'Interviewer: Ok. So would you say you had a positive experience with the service in general?

Beneficiary: Oh yeah, very. Very positive. In fact I would have recommended it to colleagues, you know I've spoken to them and said I think you need to have a word with this service, with My MS, and they should be able to help you.

Interviewer: Oh great, well that's good endorsement then. Is there anything you wanted to add that I might have missed?

Beneficiary: No, I just think it was really nice the person, he actually when we filled in the forms they wanted me to come in for a meeting, the people who do the PIP, we

had to go to Cardiff, to meet these assessors, [project officer] said that he would come and just – and to be honest he came in, I think he was there just as a general support, it wasn't that I needed him to come and speak on behalf of myself or my wife, he was just there just asking little things as questions were being asked and he was asking me to do things or whatever, whatever they do, [project officer] was there really supportive, and uh no it was really nice. With [project officer], I told my friend to get in touch with him because they needed some help as well, which is someone I've met through the MS Society, and um I said you know get in touch and I'm sure they'll be able to help.' (Interview with Beneficiary)

In this quote, the beneficiary goes into detail about the positive experience they had with the My MS service, particularly around their PIP assessment. They describe how the My MS project officer attended their PIP assessment as moral and emotional support, and how beneficial this was to them. They also noted that they had such a positive experience with the My MS service that they recommended the service to a friend who also has MS.

'Interviewer: Would you say the service has had an impact on your general well-being?

Beneficiary: Yes it has, you don't feel isolated if you need help with anything just phone them' (Interview with Beneficiary)

We can see from the above quote that the My MS service has had a positive impact on the beneficiaries' sense of well-being. They confirm that the service has had an impact on their well-being, and that it has also helped with their sense of isolation as they note 'you don't feel isolated if you help with anything just phone them.' This quotation shows that the My MS service is meeting its desired outcome in respect of having a positive impact on beneficiaries well-being.

'Well yes it has, because now I'm able to get out of my flat and go places on my scooter and you know obviously because I had the enhanced amount donated, that wasn't donated, because I had the enhanced benefit rate, I was able to you know do different things, get out of the flat on my scooter and you know meet up with my friends, different things than you would normally do.' (Interview with Beneficiary)

Here the beneficiary reflects again on the ways in which the My MS service has had a positive impact on her well-being. She notes that assistance with the PIP benefit and in applying for a grant for her scooter has enabled her to be more independent, get out more and therefore be less isolated than she would've been if she hadn't used the My MS service.

SUMMARY OF BENEFICIARY INTERVIEWS

We saw from these interviews with beneficiaries and carers of beneficiaries a variety of perspectives on the My MS service. We saw how people came to be involved in the service, frequently via external referrals through hospitals and specialist MS nurses. We saw the support needs that people had, from dealing with PIP benefit, to having someone to speak to who understands MS, to applying for grants for assistance with practical issues. All these support needs were met by the My MS service.

We then saw the experiences that people had with the My MS service, and these have been overwhelmingly positive, with individuals citing substantial improvements in their financial security, well-being and independence. The way in which the My MS service and staff combine practical and technical knowledge (on things like benefits, courses, grants, and housing) with emotional and pastoral support has been of invaluable benefit to beneficiaries and carers, and strongly suggests that the My MS service is meeting several of its stated outcomes, particularly around financial security, well-being and independence for beneficiaries.

AREA STAKEHOLDER BOARD FOCUS GROUPS

The My MS, My Rights My Choices service has, since its inception, encouraged MS Society members and beneficiaries of the service to become involved in area stakeholder boards. This gives an opportunity for stakeholders in the service in the regional areas (South West Wales, South East Wales, North West Wales, North East Wales) to get together and meet with their regional project officer to feedback on how the project has been developing, what the challenges are and what the benefits have been. As part of the evaluation, we conducted focus groups in three of the regions (South East Wales, South West Wales, and North West Wales) regular stakeholder meetings, to get a sense of the perspective of the

area stakeholder board members on the My MS project. Data collected in these focus groups is presented below.

Area Stakeholder Board Activities and Impact

We asked area stakeholder board members what activities they were involved in as stakeholder, and what impacts they felt the area stakeholder boards had on the My MS project's development. A selection of pertinent responses are presented below:

> *'Group Member: When it initially started, you know it was what target areas to look at from a group perspective, what pockets of concern, whether it was benefits related, whether it was lifestyle changes and things like that and what we're seeing from the ground so to speak is how can we have an impact on that, and how can we direct the project in the way that it needs to go*
>
> *Group Member: Where was the reach, and where wasn't the reach really.' (Focus Group with South East Wales Area Stakeholder Board)*

We can see from this extract from the focus group with the South East Wales stakeholder board that part of the purpose of the stakeholder boards was to identify target areas for the My MS project to look at. Which areas of their lives would people need support with? They also discuss identifying where the project had reach, and where it did not. We can see from this extract that the area stakeholder boards had a central part to play in developing the My MS project.

> *'And its values in the figures itself….England, Scotland and Northern Ireland don't have anything like this….you have to ask yourself if this didn't exist how many of these figures would be told later on….these people have actually benefitted either directly or indirectly….whether it be financial support…saying well if you do this your carer can actually get a benefit as well….did you know that…it's not just you getting the benefit….the carer themselves can be financially assisted to maintain sustainability and quality of life that cos at the end of the day what this has delivered is quality of life that had this not existed before those people wouldn't have known or benefitted from…' (Focus Group with South West Wales Area Stakeholder Board)*

This extract details how they feel the My MS service has benefitted beneficiaries by delivering improvements in quality of life and knowledge around benefits and other services available to those with MS and their carers. Part of this is informed by the stakeholder board activities in feeding back needs to the project officers of people with MS, e.g. in this instance the awareness that carers can receive benefits also.

Impact of Area Stakeholder Board Activities on Individuals

We asked people what they thought the impact was on them as individuals in being involved in the area stakeholder boards. Some of their answers are presented below:

> *'Group Member: It gives us a voice really, it empowers us to have that knowledge and passing that knowledge on so that when you're seeing people about in the community that there is that hope.' (Focus Group with South East Wales Area Stakeholder Board)*

> *'It's also a case of nothing about us without us…you know we have to be part of the whole process, you know accountability and putting your foot forwards…you probably know yourself so many other charities are by people who know what's best for us.' (Focus Group with South East Wales Area Stakeholder Board)*

The quotes above highlight the impact that the area stakeholder boards have on individuals who take part on them. The first quote suggests that being involved as an area stakeholder board member enables people living with MS to 'have a voice' and that it is empowering to be able to have knowledge about the project and pass that knowledge on to people in the MS community.

The second quote notes how important the area stakeholder boards have been in the development of the My MS project. The stakeholder states eloquently that there is 'nothing about us without us' and that they feel the project has been developed via input and engagement with people living with MS, rather than other charitable projects which have been developed by 'people who know what's best for us'.

Effect of My MS Project on Local MS Groups

We asked the area stakeholder boards what they felt the impact of the My MS project has been on local MS groups and the MS community in their local area.

> *'I think this group was like a catalyst, and it started things off, oh there's other groups, there's other projects coming around, and it's all stemmed from when you've had your grant from the beginning, and other people thought 'oh well we'll try for one too' (Focus Group with South East Wales Area Stakeholder Board)*

> *'You know, one lady we had at group, that was the first time she'd been out of her house for two years, and so she only comes – she comes to group now once a month, and to get her to do boccia, 'oh I don't know' come on, have a go! You know? And she really enjoyed it, didn't she? And we've got curling as well, and doing archery in the new year.' (Focus Group with South East Wales Area Stakeholder Board)*

We can see from the above quotes that the area stakeholder board members felt that the My MS service has had an impact on local MS support groups and the local MS community. The first quote states that the area stakeholder group themselves acted as a 'catalyst', and that other local MS groups grew from there and attempted to apply for grant funding as well. The second quote highlights the impact that local MS groups can have for individuals living with MS, noting a case of a women who hadn't left her house for two years, and now she attends a group once a month and attends boccia matches as well. They also note that they also have curling groups and archery groups for those with MS in the area as well. This shows that the My MS service and its stakeholder board meetings are helping the My MS service meet its outcomes in respect of increased participation in the local community (Outcome One), being better informed about social and leisure activities (Outcome Three) and improved well-being and independence (Outcome One).

SUMMARY OF AREA STAKEHOLDER BOARD FOCUS GROUPS

We can see from this section of the report that the area stakeholder boards provided an important outlet, both for MS Society members and My MS stakeholders, and the project staff and its development. Area stakeholder board members helped to guide the project development by feeding back the needs of those living with MS to My MS staff, and helped hold the project to account by noting where it has reach and where it does not. We can see

that the stakeholder boards help give those living with MS a voice, particularly in the development of this project, and that they feel that the project has been developed with input from those living with MS, rather than people who feel they know what's best for them (but may not). Finally we can see the impact that the area stakeholder board meetings have on local MS groups and the local MS community, with one member describing them as a catalyst for the formation of local MS groups, and another noting the impact that local MS groups have had on individuals living with MS, in terms of their social lives, leisure choices and interactions with the local community. This points to the ways in which the area stakeholder board groups help the My MS service to meet its outcomes, specifically around participation in the local community, improved well-being and independence, and being better informed about social and leisure activities.

EXTERNAL STAKEHOLDER INTERVIEWS

As part of the evaluation, we also took the time to speak to external stakeholders involved in the My MS project. This took the form of four interviews with five people, who were all in some way employed in clinical roles associated with MS (e.g. MS nurse, or MS specialist). These are presented below, underneath sub-themes based on the pertinent questions we asked in interviews.

Support Needs for My MS Referrals

We asked external stakeholders what support needs their patients had when they were referring them to the My MS service. Their responses are presented below.

> *'So the vast majority are patients who are going through the application process for benefits, I mean there's a smaller number of patients who I've referred to so that they could be in touch with the MS Society, in relation to you know what meetings are available locally and what groups they support locally, because I don't really have knowledge of that because North Wales is a really large area so there's a smaller number of patients that I've referred for that reason, but the vast majority is to do with benefits claims. Yeah, so people who are applying for the first time, or people that are switching over from DLA to PIP, and obviously patients that have had their benefits taken away or rejected, and kind of needed a significant amount of support in relation to that.' (Interview with External Stakeholder)*

'I think that um basically what we did is uh we had people who were having problems with PIP claims and things like that, sorry we had written a list now and I've gone and lost it, yeah legal advice as well, and if people had had a change in personal circumstances as well, and looking at their support groups.' (Interview with External Stakeholder)

We can see that for the above quotes from external stakeholders, much of the referrals to the My MS service were around PIP benefits. The first quote notes that the 'vast majority are patients who are going through the application process for benefits' however she does also note that some people are referred so people are aware of local MS support groups as well. The second quote also confirms that most people are referred for advice on the PIP benefit, but that they may also be referred for legal information, changes in personal circumstances and information on local support groups.

Referral Process

We asked external stakeholders how they found the process of referring patients to the My MS service. A selection of their answers is presented below.

'Its been absolutely fine, so it's a simple matter of sending them an email, and they take from there, I'll either send them an email myself – it depends on the patient really, most of the time I'll send to patients here's their contact number, get in touch with them, but if I think that a patient might need just that little bit more support with them, I will say to them you contact them but I'm also gonna email them with your contact details and they'll get in touch with you, patients when they've got cognitive issues and um things like that can find it even difficult to make that step as well, so um emailing is fine' (Interview with External Stakeholder)

'Yeah its been fine, we've had no complaints regarding that, and generally we give out My MS staff contact details and they can contact her directly, we sometimes do it on their behalf, you know they're having problems, you know leave a message with My MS staff member and ask them to contact her directly' (Interview with External Stakeholder)

We can see here that for these external stakeholders the referral process to the My MS service has been straightforward and accessible. Those in clinical roles either email My MS staff with the patients details, or pass on the My MS staff members contact information to the patient so they can contact the My MS service directly.

Overall Impact of My MS Service

We asked external stakeholders what they felt the overall impact of the My MS service had been, both on its beneficiaries and for the stakeholders themselves in their own working practice. A selection of these responses are presented below.

> *'Um, I think from my point of view I think what they're offering is good cause it takes – before they were in post, I was trying to help people do things but I just didn't have the capacity to do it, not always in a timely basis either, so I think I don't know that there's much more they can – I mean there probably are some more things they can offer, I know that I think they have offered to help people in their work situations and things like that, maybe trying to get people back into employment, its an area that I do quite a bit with as well, but it is again supportive, and im the only person doing my job in North Wales, possibly up to 1100 people in North Wales anyway, its difficult to do it all.' (Interview with External Stakeholder)*

We can see from this quote that the impact of the My MS service for external stakeholders in clinical positions has been twofold; one, the impact on beneficiaries in terms of assistance with benefits and employment, but also the second impact being on the stakeholders work capacity itself. The My MS service may have relieved some pressure on clinical MS staff who have previously been trying to deal with MS patients non-clinical support needs, such as assistance with benefits.

> '*Absolutely, I mean the feedback I've had verbally from patients has been fantastic, and its something we just didn't have before, when it was – patients were kind of relying on me or my colleague who's an OT to give them some advice, but we're kind of sending them away with you know go look it up, we just don't have the knowledge of the benefits system, so for myself my appointments with patients are 30 minutes, and if anyone was to look at the NICE guidelines for MS Care, in that 30 minutes I'm expected to do a comprehensive of every aspect of MS, education, emotional side of*

things, something like benefits claims can really take you know a lot of time and its time and knowledge that I don't have to be able to refer patients to somebody who can sit with them and spend time with them, cause its such a significant impact on people's lives, people are transitioning from being in the workplace to not being able to fulfil their roles perhaps as much as they used to, so they're reducing their hours they're changing their job roles, and we need some financial support with that, and you know as you know the government are really clamping down on who – its not a balanced system at all, but who gets these benefits so you know its difficult for people to navigate this system, you know they're the MS Society um project officers have been superb in my opinion.' (Interview with External Stakeholder)

When feeding back on the overall impact of the My MS service, this external stakeholder picked up on similar themes as the previous quotation: the lack of capacity for clinical staff to deal with non-clinical issues for MS patients, the ways in which the My MS service has helped free up capacity and given them a useful referral and signposting point for MS patients who need assistance with issues around benefits and other practical issues. She notes the assistance that the My MS service gives to patients that she refers, and finishes by saying she feels the 'project officers have been superb.'

SUMMARY OF EXTERNAL STAKEHOLDER INTERVIEWS

We asked external stakeholders why they were referring MS patients to the My MS service, and they responded by highlighting support needs in regard to PIP benefits, employment issues and information on local MS support groups. We asked them how they found the referral process to the My MS service, which was seen as straightforward and accessible. We then asked what they felt was the impact of the My MS service, and this was seen by clinical staff as twofold; one, the obvious impact of the My MS service on beneficiaries and their support needs, but two, an impact on clinical staff capacity and ability to signpost patients to a relevant service that could help them with their non-clinical needs. Here in this section we can see the knock-on positive effect that the My MS service has had on other organisations that deal with people living with MS.

CONCLUSIONS

We can see from the results of the evaluation that My MS, My Rights My Choices service has had a positive impact on people living with MS in Wales. We saw in the opening chapter the ways in which the My MS service sits in alignment with Welsh Government policy on social care and well-being, specifically with the National Outcomes Framework and the Social Services and Well-Being Act. We saw from the second chapter, the survey results, the positive answers that beneficiaries gave, in terms of their experience of the My MS service, how they were treated, whether they achieved greater financial security because of the service and whether they would recommend the service to others with MS. The results from the survey were overwhelmingly positive for the My MS service, and showed the impact it is having on its beneficiaries, as well as the ways it is meeting its stated outcomes.

We then dedicated a chapter to the Personal Independence Payment and the support that the My MS service provides in respect of this benefit. This had been a major theme of the evaluation and it provided such rich data that it felt pertinent to explore it as a whole in one chapter. We saw from beneficiary interviews the ways in which they were supported through the PIP process, from My MS staff offering emotional support due to the panic and anxiety caused by the benefit claim, to the way they would meet people at their homes, help them fill out the forms, join them for PIP assessments and attend PIP tribunals with them. We then reflected on the PIP tribunal process with two staff members of the My MS project, who outlined the labour that goes into preparing for PIP tribunals, their 100% success rate, and the ways in which assisting people with the PIP tribunals was a combination of practical and technical knowledge, and emotional and pastoral support through the process. This really shines a light on what the project officers do; they occupy a role that straddles both technical and practical expertise and knowledge, and emotional and pastoral support for beneficiaries. We then finally saw some of the financial data provided by the My MS staff on the financial increases in benefits they have achieved for beneficiaries who have gone to tribunals. This data helps to assert that the service is meeting Outcome Four, greater financial security for beneficiaries.

We then explored further the interviews with beneficiaries and carers, identifying the ways in which My MS beneficiaries had heard about the service (frequently through a clinical stakeholder, such as an MS nurse or specialist at the local hospital). We also asked them what support needs beneficiaries had, and this was predominantly support with PIP benefit, there was also support with employment situations, signposting to local MS groups, and courses on mindfulness and fatigue management. We asked what their overall experience of the My MS service had been, and again insights here were really positive, with people noting the impact on their sense of well-being, a positive impact in terms of getting out into the community and socialising, and assistance with applying for grants for things like scooters and ground rent.

We saw from the focus groups with the area stakeholder board the ways in which its members have been involved in shaping and developing the My MS project from the beginning. We saw the impact being involved in area stakeholder activities had for members, giving them a voice in project development and ensuring the project was receiving input from those people who live with MS. We also saw the impact that the My MS project has had on local MS groups, with one person calling the area stakeholder board meetings a 'catalyst' for other MS support groups to form, and another person highlighting how important the creation of these MS support groups can be for individuals engagement in the community.

We saw from the interviews with external stakeholders in clinical MS roles the ways in which they have been referring MS patients to the My MS service, the support needs that these individuals have (usually around PIP, but also around employment, housing, and local MS support groups) and the ways in which the My MS service has benefited not only patients and beneficiaries, but also external stakeholders themselves, by freeing up capacity and giving them an appropriate location to signpost MS patients for assistance with non-clinical needs. This positive interaction with external stakeholder agencies also stands the My MS service in good stead with the Multi-agency principle of the Social Services & Well-Being Act.

Overall, we can see the extent of the positive impact that the My MS service has had, on beneficiaries, carers, local MS groups, area stakeholder boards and external stakeholders in clinical positions. The service has had an unequivocally positive impact on its

beneficiaries, and the evidence in this evaluation shows how this has been achieved. This means that the My MS service has met its stated project outcomes, sits in alignment with Welsh Government policy, and provided a profoundly important service for people living with MS in Wales.